

# Periodic health examinations for adults with developmental disabilities

*Are we doing enough?*

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Recent research has demonstrated that adults with developmental disabilities (DD) have higher rates of emergency department visits,<sup>1</sup> hospitalizations, and hospital readmissions<sup>2</sup> than those in the general population. Furthermore, they are more likely to be admitted to hospital for conditions that are generally well managed in primary care.<sup>3</sup> It has been suggested in Australia<sup>4</sup> and the United Kingdom,<sup>5</sup> as well as in the “Primary care of adults with developmental disabilities. Canadian consensus guidelines” (hereafter referred to as the *2011 Guidelines*),<sup>6</sup> that one way to prevent mortality and morbidity in adults with DD is through comprehensive primary care with a focus on preventive health care. Most often, preventive care is undertaken during the periodic health examination (PHE). In the United Kingdom and Australia, physicians receive financial incentives to conduct these preventive examinations for their patients with DD. Here in Canada, the PHE for such patients is reimbursed as it would be for the general population despite it taking more time and being more complex in those with DD. The 2011 Guidelines advise primary care providers to “perform an annual comprehensive preventive care assessment including physical examination and use guidelines and tools adapted for adults with DD,” a recommendation based on level I evidence.<sup>6</sup>

How closely do primary care providers follow this guideline? We asked this question as part of the H-CARDD (Health Care Access Research and Developmental Disabilities) program. We created a cohort of more than 65000 adults younger than age 65 with DD living in Ontario and examined the proportion of them who received PHEs across a 2-year period (fiscal years 2009 and 2010 to 2010 and 2011). During our analysis of these data, we found that only 22% of adults with DD received this type of examination during the 2 years. This is slightly lower than the rates we found for the general population (26%).<sup>7</sup>

Given that the 2011 Guidelines recommend these examinations in order to prevent disease and promote health, we consider it problematic that these visits are only occurring in about 1 in 5 adult Ontarians with DD. The low rate is not because these patients cannot access primary care, nor is it because they cannot access enough primary care.<sup>8</sup> Approximately 3 of 4 adults with DD that we studied saw

primary care physicians at least once in a 1-year period (fiscal year 2009 to 2010), and those that did so made a mean number of 5.8 visits.<sup>9</sup> It appears that primary care physicians are responding to the concerns of their patients with DD when they are brought to their attention; however, they are missing opportunities to take a proactive and preventive approach to the care of these patients.

## Barriers

One commonly mentioned barrier to the provision of quality primary care is the time it takes to obtain an adequate history from people with DD owing to difficulties with communication, compounded by multiple medical comorbidities.<sup>10</sup> Models of care that include physician remuneration to compensate for the increased time requirements have been successfully introduced in other countries.<sup>4,5,11</sup> Since 2006, Australia has been funding general practitioners to perform annual health assessments for their patients with DD (\$269.03) based on evidence that these assessments lead to earlier identification of health issues and prevention of more complex difficulties.<sup>4,10</sup> Wales has also been funding DD annual health assessments since 2006<sup>11</sup> (\$158.72), and these health examinations have been funded across the United Kingdom since 2009.<sup>5</sup> A 2009 study conducted in Scotland demonstrated that these health examinations were inexpensive and had lower associated caregiver costs in the following year than caregiver costs for those receiving usual care.<sup>12</sup>

Another barrier is related to the discomfort that physicians have with serving this special population. A study in which family physicians in the United States were interviewed found that although these practitioners tried to provide care for their patients with DD, they did not believe they were knowledgeable about this population and lacked the resources and support they needed to provide good care.<sup>13</sup> Models of primary care that take a team approach combined with enhancing training to work with patients with DD would be a way to address this barrier. In Ontario, family health teams and community health centres with their interdisciplinary approach to disease management and closer ties to community and social services might be ideally suited to care for this population, and it might make the most sense to invest in training in such settings.

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Cet article se trouve aussi en français à la page 115.

## Mechanisms of change

It might not be enough to introduce new care guidelines and changes in screening recommendations for physicians; they need to be convinced that these are appropriate changes to make and they need practical guidance on how to initiate these changes. In Ontario, support networks are being developed regionally to assist primary care providers in the day-to-day management of their patients with DD. Another mechanism to encourage change within primary care for people with DD might be through feedback to providers about their preventive care (eg, cervical cancer screening, colorectal cancer screening), disease management (eg, diabetes), and health care (eg, emergency departments visits) outcomes. Generation of such data could also serve as a scientific foundation for the current and possibly future recommendations.

We need to improve our care of adults with DD here in Canada. What will it take for us to make sure that more adults with DD receive PHEs? Financial incentives have been associated with improved preventive care for the general population,<sup>14</sup> but can they help people with disabilities? Can guidelines and commentaries make a difference? Is more training required? Can giving feedback to providers about the care their patients with DD receive promote change? Do we look for leadership from family physicians or do we educate families and people with disabilities to visit their doctors more regularly for this type of examination? In May 2011, in addition to receiving the revised primary care guidelines, all members of the College of Family Physicians of Canada received a copy of clinical tools to assist them in the care of their patients with DD.<sup>15</sup> These tools included tips on how to communicate and organize office visits and provided a preventive care checklist, which is available free online,<sup>16</sup> that highlights areas of importance to adults with DD.<sup>16</sup> Also in 2011, a special interest program in DD was established within the College of Family Physicians of Canada. There is an increasing interest in the population with DD in Canada, and there is much we can learn from our colleagues in other countries. The H-CARRD program will continue to calculate PHE rates to monitor patterns over time and to evaluate the effect of various initiatives, such as incentives based on patient complexity, or training in the care of people with DD at the undergraduate or postgraduate levels and among all primary care providers. We have identified the problem and now we need to move forward with some solutions in a Canadian context. 🌱

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### Competing interests

None declared

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